



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
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March 14, 2001

TO: Washington State Board of Health Members

FROM: Doreen Garcia, Senior Health Policy Advisor

RE: CR-101 - Proposed Intention to Modify Regulatory Standards for Newborn Screening

Background and Summary:

The Washington State Board of Health is responsible for Washington's newborn screening law (Chapter 70.83 RCW; Phenylketonuria and Other Preventable Heritable Disorders). The Board is directed to adopt rules and regulations necessary to carry out the intent of the chapter and the law directs the Department of Health to require screening of all infants for phenylketonuria (PKU) and other disorders that the Board determines as necessary.

Current regulation in WAC 246-650 requires screening of newborns for four disorders: Phenylketonuria (PKU), congenital hypothyroidism, congenital adrenal hyperplasia and hemoglobinopathies such as sickle cell disease. The Department of Health does the testing at the state public health laboratory supported by a fee that is collected through the hospital or other birth facility.

Medical and technological advances in recent years have made it feasible to screen newborns for an increasing number of disorders. Many can be detected using the same dried blood specimen that is routinely collected to test infants for PKU and the other disorders. For example, a technology called tandem mass spectrometry (MS/MS) is being heavily promoted by a number of organizations, individuals and parent groups. This technology can detect over 30 different disorders in newborns. However, many of the disorders do not fit classic criteria for population based newborn screening: they are extremely rare and effective preventive treatment is not available. The March of Dimes has identified 8 core newborn screening tests that they advocate for including in every state newborn screening program. At the same time, Washington is now the only state in the country that does not screen its infants to detect

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galactosemia, a congenital metabolic problem that can cause sudden unexpected death and severe physical defects. There is increasing public concern that Washington is not performing these additional screening tests.

Recommended Board Action:

The Board may wish to consider, amend, and approve the following statement:

The Washington State Board of Health directs the Executive Director to file a CR-101 announcing the Board's intention to review WAC 246-650 to consider amending the newborn screening rule to include which, if any, additional disorders should be included in the mandatory dried blood spot screening.